

When her infant daughter, Francine, was diagnosed as mentally retarded 43 years ago, Theresa Eppolito never thought of putting her in an institution. She would raise Francine in her home in Brooklyn. N.Y. Today, Mrs. Eppolito is 70 and undergoing chemotherapy for cancer. Her husband, Frank, a retired barber, is 78 and ailing. Francine, at 44, is unaware of her parents' fear that she will lose her freedom the moment they are gone.

Fairbury, Neb., is a farming community of 4800 souls. Four blocks from the center of town is a workshop employing 28 mentally retarded adults, most of who had been institutionalized before moving to Fairbury. These people live and work in Fairbury because the town not only said it wanted them but also outbid another community to get them. The city promised—and delivered on—facilities, home services and, above all, community support.

USEFUL LIVES USEFUL PEOPLE

BY LEONARD GROSS

THIS STORY, AS THE examples above suggest, begins with despair and ends with hope.

We Americans perceive ourselves, not inaccurately, as a kind and charitable people. But the treatment of our mentally retarded has been a blind spot. We lavish attention on mentally retarded children. But once these children grow up, the record shows, we shut our eyes or look the other way.

"People with Down's syndrome are cute when they're little," observes Jean Elder, commissioner of the government's Administration on Developmental Disabilities. "They're not cute when they're older." Says the anthropologist Robert Edgerton, an authority on mental retardation: "Kids get all the attention, and no one gives a damn about the adults. They're generally trashed."

A large part of the problem, according to Miles Santamourof the President's Committee on Mental Retardation, is that "the general public confuses mental illness and retardation, and there's a world of difference between the two." A mentally ill person, he explains, is unable to function because he is confused, whereas someone who is retarded is intellectually impaired or "slow."

There are four categories for the retarded: *profoundly*, with an IQ under 20; *severely*, with an IQ of 20 to 35; *moderately*, with an IQ of 36 to 49; and *mildly*, with an IQ of 50 to 69.

In the United States, says Santamourof, there are 6.9 million retarded people. Almost 6.2 million of them are classi-



Dennis Weinbaum, 39, is an office aide for New York City's Department of Health

fied as mildly retarded and general are not readily identifiable. The moderately, severely and profoundly retarded then, add up to about 700,000. Of that number, roughly half are older than 1

Until relatively recently, doctors would recommend that mentally retarded persons be institutionalized "for the good of the family." An unexpressed—a perhaps unconscious—public repugnant underscored such policy. As Louis Brown, a professor of special education at the University of Wisconsin, puts it, "You see a busload of retarded kids, you say, 'Aw, gee.' You see a busload of adults, you're more repulsed by them, scared of them, afraid they might hurt you in some way physically or sexually."

When the mentally retarded are made part of society—everyone benefits

Beginning in the late 1960s, however, a series of exposés alerted the nation to the hideous conditions that often accompany the wholesale warehousing of the mentally retarded. The Nixon Administration began a concerted effort to reduce the population of public institutions, which housed nearly 200,000 mentally retarded people across the country. Today, there are roughly

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USEFUL LIVES/continued

120,000 such residents. (In addition, 115,000 retarded people live in 14,600 private institutions.)

But, with the Nixon initiative, troubles began.irate citizens, resisting the shift of retarded people into group homes, protested that property values would be eroded. So vehement were the protests that at least 31 states passed laws prohibiting discrimination against the retarded. Recently, the Supreme Court ruled that the town of Cleburne, Tex., could not prevent a group home for retarded adults from being built in a residential neighborhood.

Study after study has demonstrated that group homes do not erode property values, but many Americans still refuse to believe that. One result of such negative attitudes can be seen in the New York City area. Despite the fact that the Young Adult Institute has established group homes for 300 retarded adults, 600 remain on its waiting list. (Thousands released from institutions since the Nixon era also need homes.) Some estimate that there will be a shortage of 9000 beds in the state by 1991.

No law protects handicapped adults. "Aging out" is the term social workers use to describe what happens when an intellectually, physically or emotionally deficient person reaches 21. Since states stop most funding without insuring that appropriate alternatives are available, hundreds of young people who "age out" each year end up with families unequipped to care for them—or on the streets.

The work situation is no better. Many of the mentally retarded do manage to find support, often in daytime workshops. But rather than graduate their workers—as their charters mandate—the workshops often hold onto the better ones to enhance production. Those who do move on to independent work face another penalty—a drop in Social Security benefits that leaves them poorer than they would have been if they hadn't worked at all. Says Pam Scoggins, a volunteer for California's program for the developmentally disabled, whose own learning disability does not keep her from being articulate: "If somebody does too good, they're punished by society."

Perhaps the most pathetic victims, however, are those like Francine Eppolito, who face the consequences of a second "aging out"—the imminent death of their parents. The system has no provision for their care. What makes this so ironic is that, by deciding to care for their children themselves, such parents have, over the years, saved the taxpayers a fortune. One mother of a retarded man in his 30s recalls attending the funeral of another retarded man the same age and thinking how lucky his parents were. "We pray our children will predecease us so that we can provide whatever is necessary," she says. "It's not easy to



Alan Cohen, 32, is a mail messenger for McGraw-Hill. The Young Adult Institute, which establishes community residences for retarded adults, got him his job.

say, but it's exactly how I feel."

The heart of the problem is not laws or housing but the widespread assumption that retarded adults are waste material, incapable of development.

There is evidence that this attitude may be changing. Across the nation, what Commissioner Elder describes as "islands of excellence" are proving that mentally retarded persons can be integrated into society—to everyone's profit.

- In Rhode Island, 1260 mentally retarded persons were living in the Dr. Joseph Ladd Center in 1972. There are fewer than 400 there today, following a concerted effort on the part of the state to find community housing for the residents and to discourage new admissions. The average cost of community living arrangements is \$21,900 a year per person, compared with an institutional cost of \$50,000. (Rhode Island spends \$50 million a year on its retarded, \$30 million of which is reimbursed through federal aid via Medicaid.)

- Using foster homes, group homes and semi-independent apartments, the Macomb-Oakland Regional Center north of Detroit has placed 1200 mentally retarded persons in the community. Cost: about \$25,550 a year for each person, compared with \$49,275 in institutions.
- In Boston, Transitional Employment Enterprises has placed more than 300 supposedly unemployable mentally retarded people in bona fide jobs in the private sector. Backed by private and state funding, Transitional takes the initial risk of training the employee; the

employer eventually pitches in. "We try to persuade the private sector to hire people because it's in their interest," says James Kenney, the company's director. For each person moved from the public to the private sector, he estimates, the yearly tax saving is \$5000.

- In Madison, Wis., 38 of the last 50 mentally retarded persons to graduate from high schools have found jobs in the private sector. Only a few years ago, they all would have worked in sheltered workshops. Savings to taxpayers: \$3600 a year per person.

- Spectrum Center of Berkeley, Calif., has set up 24 persons in four group homes for the mentally retarded in recent years, against heavy community opposition. Each home saves the state approximately \$150,000, according to Randy Keyworth, the center's director.
- In Nebraska, 2244 retarded persons are being cared for in the community. The number of persons in the state institution, meanwhile, has dwindled to a fifth of what it was. Savings to taxpayers: \$24,860 a year per person.

Since the public's attitude has been the underlying problem, the excellent experience of Fairbury, Neb. bears close examination. Lyn Rucker, director of one of the state's regional offices of mental retardation, recalls what happened: "We asked ourselves. After all these years, why are we so stupid? We consider ourselves a business. Why don't we act like one?" We went to the mayor, chamber of commerce and city council, and we said. Our smallest program has

an annual budget of \$500,000. We told them how many people we'd employ, what products we'd be producing, what kind of real estate we'd need, how many groceries and other products we'd be buying. We said. Are you interested? They said. Are you kidding? "

Five years ago, the first 16 mentally retarded adults moved into several rented homes. There was some discomfort at first: unwitting discourtesies, some hostile stares, some grumbling threats to get up a petition. But store owners opened early for the new neighbors so that they could learn how to shop, and the Methodist church held special Sunday afternoon services to teach them how to worship. Today, there are no more stares and there is no more rudeness, and the retarded residents make their store purchases during regular hours.

The cost of maintaining each retarded person in Fairbury is \$24,000 a year—as opposed to \$34,000 a year in the nearby Beatrice State Developmental Center, whose officials, Lyn Rucker says, were profoundly skeptical of the move. "They told us we'd never have the people eating in McDonald's," she recalls. "We had them there in two weeks. They told us they wouldn't last two weeks. We've had them here five years."

Nationwide, deinstitutionalization is still resisted, particularly by older parents of retarded adults. They're used to the present arrangement: they worry that the group homes could go bankrupt. There's resistance as well from unions representing workers whose jobs might be lost. Even today, a decade after deinstitutionalization began, the institutions still get the lion's share of the money.

But Dave Powell, director of the Nebraska chapter of the Association for Retarded Citizens, believes that this nation's treatment of mentally retarded adults is on the edge of a breakthrough. "We've been dealing with a population that looks on mental retardation from the charity model. Until we approach it as a business, we're going to have problems—because people aren't into charity for adults."

As significant as the financial savings are, the human profit is priceless—as Fairbury's example attests. The new residents have caught their first fish and watched their first softball game. Their workshop is productive, and three members have graduated to jobs in the community. As for fears about what would happen to the neighborhood—when one of the group homes was to be shifted, longtime resident Pauline M. Edwards went to the regional office to find out why. "We didn't want them to move," she says. "They were among the best neighbors we ever had."

For additional information, contact the Association for Retarded Citizens of the U.S., Dept. P, 2501 Avenue J, Arlington, Tex. 76006.